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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[30Day-12-11IY]

Agency Forms Undergoing Paperwork Reduction Act Review

The Centers for Disease Control and Prevention (CDC) publishes a list of information collection requests under review by the Office of Management and Budget (OMB) in compliance with the Paperwork Reduction Act (44 U.S.C. Chapter 35). To request a copy of these requests, call the CDC Reports Clearance Officer at (404) 639-5960 or send an email to omb@cdc.gov. Send written comments to CDC Desk Officer, Office of Management and Budget, Washington, DC 20503 or by fax to (202) 395-5806. Written comments should be received within 30 days of this notice.

Proposed Project

Formative Research to Support the Development of Sickle Cell Disease Educational Messages and Materials for the Division of Blood Disorders - New - National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC).

Background and Brief Description

CDC seeks to improve the quality of life of people living with sickle cell disease (SCD). To accomplish this goal, CDC aims to address the need for educational messages and materials for adolescents, young adults, adults, and older adults living with SCD. CDC is interested in understanding the informational needs of these audiences related to the adoption of healthy behaviors and the prevention of complications associated with sickle cell disease. To develop valuable messages and materials, CDC will conduct formative focus groups with people with SCD across the country. Participants will stem from four urban centers as well as more remote, rural areas. Based on the findings from the formative focus groups, CDC will develop and test draft messages.

A total of 10 focus groups will be conducted. Eight focus groups with people with SCD would be held in four cities: Atlanta, GA; Detroit, MI; Oakland, CA; and Philadelphia, PA. Two in-person focus groups - one with males and one with females - will be conducted in each city with each target audience: adolescents aged 15-17, young adults aged 18-25, adults aged 26-35, and older adults 36 and over. To reach more rural participants, two telephone focus groups will be conducted: one with female adolescents aged 15-17 and a second with male older adults aged 36 and older.

The focus groups will be conducted with eight to nine participants in each and will last 2 hours. As part of the focus group, participants will complete an informed consent or adolescent assent form before discussion begins. The parents of the expected 27 adolescent participants (three groups of 9 each) will fill out a permission form to provide their consent in advance of the groups. The use of trained moderators and a structured moderator's guide will ensure that consistent data are collected across the groups. In total, up to 90 people with SCD will participate in the focus group data collection. It is estimated that 120 potential participants will need to be screened to reach the target of 90 participants. The estimated time per response for screening and recruitment is 12 minutes.

CDC requests OMB approval to obtain clearance for one year. There is no cost to respondents other than their time. The estimated annualized burden hours for this data collection activity are 204.

Estimated Annualized Burden Hours

Type of Respondent	Form Name	No. of Respondents	No. Responses per Respondent	Average Burden per Response (in hours)
Parents of adolescents (aged 15-17) living with SCD	Participant Screener and Recruitment Script	120	1	12/60
Young adults (aged 18-25) living with SCD				
Adults (aged 26-35) living with SCD				
Older adults (aged 36+) living with SCD				
Adolescents (aged 15-17) living with SCD	Focus Group Moderator's Guide	90	1	2
Young adults (aged 18-25) living with SCD				
Adults (aged 26-35) living with SCD				
Older adults (aged 36+) living with SCD				

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